

Care and communication between health professionals and patients affected by severe or chronic illness in community care settings: a qualitative study of care at the end of life

Kristian Pollock* and Eleanor Wilson

School of Health Sciences, University of Nottingham, Nottingham, UK

*Corresponding author

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Plain English summary

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Advance care planning (ACP) is a process whereby patients, in discussion with health professionals and family members, make plans for their own future health care, based on what they would like to happen if they become unable to make decisions for themselves. Little is known about how ACP is carried out, or how it affects patients' and families' experience of death and dying. This study investigated when and how patients, family carers and health professionals communicate with each other about ACP for patients who are seen to be approaching the end of their life.

Researchers interviewed 37 health professionals, including general practitioners, community nurses and specialist nurses, about their experience of talking to patients about ACP. In addition, 21 case study patients were interviewed several times during a period of approximately 6 months. Thirteen family carers and 14 health professionals were also involved in the case studies, resulting in a total of 97 interviews.

The study found evidence that just over half (12 of 21) of the patients in the study had been involved in ACP. The considerable uncertainty of prognosis made timing of ACP discussions difficult. Professionals often faced difficulties in raising the topic and recognising when patients were ready to talk about the future. Discussion was usually limited to decisions about specific issues, including where the patient wished to die, or if resuscitation should be attempted. The difficulty and complexity of decision-making about preferences for future care, combined with the volatility of illness, frequently prompted a change of plan. Those who wished to consider ACP often preferred to leave discussion until they had become severely ill, rather than create plans in advance of a time when they might become unable to make decisions for themselves. The study findings highlight the complexity of decisions about end of life care, and the diversity of patient and family responses. In particular, they challenge the basic assumptions underlying current formulations of ACP: that patients do (or should) wish for open awareness of death, that home is always the best and preferred place to die and that place of death is a matter of over-riding importance for the majority of patients.

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